

CLINICAL PRACTICE

Telephone triage and seizure management for community-based ID/DD: A research synthesis

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ABSTRACT

Nurse and physician clinicians often guide seizure care for individuals with intellectual and developmental disability (ID/DD) through telephone triage. This article evaluated the evidence for epilepsy management tools with a focus on the telephone triage tool. Studies were included in the systematic review, data was extracted, followed by meta-aggregated findings. A rigorous methodological protocol was used as described by The Cochrane Collaboration. All quantitative or descriptive studies that included epilepsy management tools or protocols for persons with ID/DD living in a community-based setting were considered. No tools specific to ID/DD seizure management via telephone triage were discovered. Study results reveal a possible gap in clinical care. Research findings did support the use of telephone triage tools and epilepsy protocols for clinicians. These findings may improve seizure management by focusing ID/DD clinicians on the advantages of using such tools. Findings may also illuminate the need for seizure management tools specific to the ID/DD population.

Key Words: Epilepsy, Disability, Tool, Protocol, Telephone

1. INTRODUCTION

1.1 Defining developmental and intellectual disability

Developmental disabilities are chronic disabilities that can be cognitive or physical in nature or can include both. The disabilities appear before the age of 22 and are likely to be lifelong.^[1] Examples of developmental disabilities include: autism, intellectual disability, behavior disorders, cerebral palsy, Down syndrome, and brain injury. Intellectual disability is a cognitive disability characterized by significant limitations in reasoning, learning, problem solving, and adaptive behavior.^[2] This disability presents itself before the age of 18. Intellectual and developmental disabilities (ID/DD) often exist as co-conditions. Therefore, researchers will use the term ID/DD when referring to the focus population in community-based settings.

1.2 Purpose of synthesis

The purpose for conducting this synthesis is to evaluate the evidence for epilepsy management tools. The search will focus on telephone triage epilepsy management tools used in community-based settings. Community-based settings are defined as homes owned by an individual or community service provider. These community-based settings offer interventions to support individuals' health, development, and integration into the community.^[3] The target population for this synthesis is persons with ID/DD.

2. BACKGROUND

Although reported epilepsy percentage rates vary, the prevalence of epilepsy in the ID/DD population is clearly higher than the general population.^[4] The probability of epilepsy in-

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creases concurrently with the severity of the disability (mild, moderate, severe, and profound). Co-existing complications such as other neurological conditions and motor disabilities also increases the risk.^[5] Robertson et al.^[4] compared the risk for epileptic persons with ID/DD to the general population and determined an overall increase in risk mortality for the ID/DD population.

Individuals with ID/DD often have multifaceted and fragile health concerns that can increase the complexity of seizure management. Seizures in this population are oftentimes atypical in presentation making it difficult to accurately make a diagnosis. This patient population can also have multiple types of seizure activity. These multiple types can make seizure identification and treatment choices more difficult for clinicians.^[6] Individuals with intractable (hard to control) seizures are also at an increased risk for injury and death due to the underlying causes of the epilepsy.^[7]

Finding qualified health clinicians with ID/DD knowledge is problematic.^[8] Many healthcare clinicians have limited knowledge and experience related to the health needs of this population, including seizure management.^[9] This may be due in part, to the lack of formal healthcare education for clinicians in the field of ID/DD.

The article by Cervasio^[8] describes the need for nursing curriculums to include courses in intellectual and developmental disability. Currently, most instructive courses and clinical experiences do not include content on the ID/DD population. Smeltzer et al.^[10] cite absence of funding and faculty expertise as two reasons for not including ID/DD education in their curricula. Likewise, physician education may also lack health content related to persons with ID/DD. The American Association of Developmental Medicine and Dentistry (AADMD) acknowledges that most medical residents do not receive adequate training to meet the healthcare needs of persons with ID/DD.^[11]

While there have been attempts to increase education for healthcare clinicians about persons with ID/DD, most attempts have failed to produce an adequate number to provide healthcare to this population.^[12] This lack of qualified clinicians may lead to a delay in access and delivery of needed healthcare services.^[13] A delay may have serious consequences for persons with ID/DD and the comorbid condition of epilepsy.

Telephone triage is a common healthcare practice for persons with ID/DD.^[14] Due to the high prevalence of epilepsy^[3] telephone triage is a critical component of ID/DD seizure management for persons living in community-based settings. Telephone triage is a component of a larger network of

technology most often described as 'telehealth'. Telehealth modalities include phone, videoconferencing, and the use of more than one type of technology. The purpose of this technology is to provide guidance to consumers on health related issues. More specifically, telephone triage is a methodical procedure used by healthcare clinicians to screen a caller's symptoms for urgency. Clinicians often use standardized protocols during telephone triage. These protocols assist healthcare clinicians to ask the right questions to quickly ascertain the severity of the problem. The clinician then guides the caller toward the right medical intervention. By using these organized protocols, clinicians can respond to telephone calls with uniformity and confidence.^[15]

Many community health settings make use of telephone triage to augment clinical care. Beaulieu & Humphreys^[16] evaluated telephone advice in a managed pediatric community clinic. The study results reported telephone triage advice may increase both satisfaction of the patient and access to care. Individuals with mental health concerns^[17] and individuals living in rural communities^[18] frequently rely on advice received from clinicians via telephone triage.

Adding to the complexity of care, much of the direct care provided to persons with ID/DD is performed by non-licensed care providers known as direct support professionals.^[19] Direct support professionals (DSPs) may have little or no healthcare background. DSP preparation across the United States is varied and dependent on the State in which community-based services are provided. Many States mandate that DSPs receive training on health related issues. As an example, the State of Indiana require DSPs to receive certification in the education curriculum Medication Administration: Living in the Community. However, the core training excludes many health conditions including epilepsy management.^[20]

Many states also support the National Alliance for Direct Support Professionals (NADSP) program that offers health training and certification to DSPs. One of the defined DSP competencies is supporting the health and wellness of persons with ID/DD. Supporting health and wellness includes using appropriate procedures when responding to emergencies.^[19] However, there is no current mandate that requires provider agencies of community-based settings to offer this type of training to their DSPs. Given this varied educational background, DSPs often rely on clinicians to guide seizure care for persons with ID/DD via telephone triage.

In general, ID/DD clinicians are assigned a caseload of individuals who live in community-based settings. Oftentimes, these homes are geographically widespread making it difficult to be present when seizure activity occurs. Therefore, the ID/DD clinician may receive a phone call from a

DSP describing the seizure activity and requesting advice.^[21] As a result, clinicians working within the field of ID/DD are charged with providing guidance via telephone triage to DSPs before, during, and after a seizure event.^[22]

Additionally, poor salary structures and a shortage of DSPs exist.^[23] Furthermore, the DSP turnover rate is estimated to be between 40% and 70% in community-based settings;^[24] making DSP work consistency problematic. The shortage of DSPs, their potential absence of healthcare training, and high turnover rate,^[25] highlights the need for clinicians to provide guidance to DSPs in seizure management. Likewise, telephone seizure management tools are needed to augment clinicians' skill level to effectively manage seizures in the ID/DD population.

3. LITERATURE REVIEW

The American Association of Neuroscience Nurses^[26] reported there is a need for evidence-based guidelines for the management of epilepsy. In the document *Care of the Patient with Seizures* the American Association of Neuroscience Nurses (AANN) stated the necessity of providing resources and recommendations for practice in all settings. The document provides samples of obtainable epilepsy management tools in various clinical settings. Yet, nothing addresses seizure management in the ID/DD population.

Seizure management tools exist for acute care settings. These tools provide a blueprint for clinicians from the initial presentation of the seizure to the discharge planning stage.^[27] Seizure management tools are often kept at the bedside of patients diagnosed with epilepsy. These tools provide the clinician with a road map of safety interventions and supplies, including how to manage the seizure event.^[28]

Seizure management tools can be found for convulsive or tonic-clonic status epilepticus (SE). SE is defined as a seizure lasting longer than 30 minutes or two or more sequential seizures without regaining consciousness in between.^[28] Left untreated, tonic-clonic SE can lead to transient or even permanent brain damage or death.^[29] The tools for SE guide the clinician on appropriate medication choices. The tools also direct clinicians towards proper medical monitoring such as examining the heart, checking brain activity, and managing the airway.

Tools for the management of persons having a suspected first-time seizure are accessible in the literature. These tools guide the clinician from the suspected seizure event, to the diagnosis, and the planning phase of care.^[30] Seizure management tools are available for clinicians whose patients have intractable seizures, resistant to common treatment options. These pathways assist in determining the underlying cause

of the epilepsy. Identifying the cause enables the clinician to choose the best treatment alternatives.^[31]

Long-term management of seizures as a chronic condition can be found. General guidelines and training materials for clinicians are available through varied organizations. One organization is the National Institute for Health and Care Excellence (NICE).^[32] NICE provides online materials for the management of epilepsy for children and adults. However, the materials do not include recommendations specifically for individuals with intellectual and developmental disability and does not include a telephone triage tool.

Seizure management tools are also available for status epilepticus (SE) in secondary settings such as school and the workplace. These tools provide guidance for medication administration to help control SE.^[33] The tools also provide recommendations on how to document SE, administer first-aid^[34] and educate the general public on SE recognition.^[28]

4. METHODOLOGY

A research synthesis uses a systematic review process that plans orderly steps and independent review of research studies in order to address a distinct topic.^[35] Relevant studies were included in the systematic review, the data was extracted, followed by meta-aggregated findings. A rigorous methodological protocol was used as described by The Cochrane Collaboration.^[36]

A multiple database search strategy of the literature was developed for seizure management tools for persons with epilepsy in community-based settings. Studies retrieved were evaluated for inclusion and then were critically appraised. Findings from each study were described then summarized, and clinical implications were addressed. Exploring studies that have the same phenomenon of interest allows for in-depth analysis and presentation for a directional conclusion that has potential clinical significance. When research findings are combined, synthesis can address the specific research question.

4.1 Search strategy

Database searching included Web of Science, CINAHL, Academic Search Premier, Medline and Google Scholar from 2000 through 2016 in order to conduct a broad review of the most important studies in this century. The literature search intended to locate articles with key words of epilepsy, disability, tool, protocol, and telephone via the search process. After removing research studies that did not meet the search criteria, a total of 11 were included for critical appraisal. A backward citation search of each of the 11 studies selected resulted in a total of 216 references. After duplicate

sources were removed, there were two additional references for consideration with only one meeting the inclusion criteria. One paper from the American Association of Neuroscience Nurses obtained from the organizational website was added for a total of 13 studies (see Figure 1) in this synthesis. Pa-

pers were excluded that did not address our purpose, epilepsy tools, or the intellectually disabled population. Also, non-English language and duplicative studies were removed from the final results.

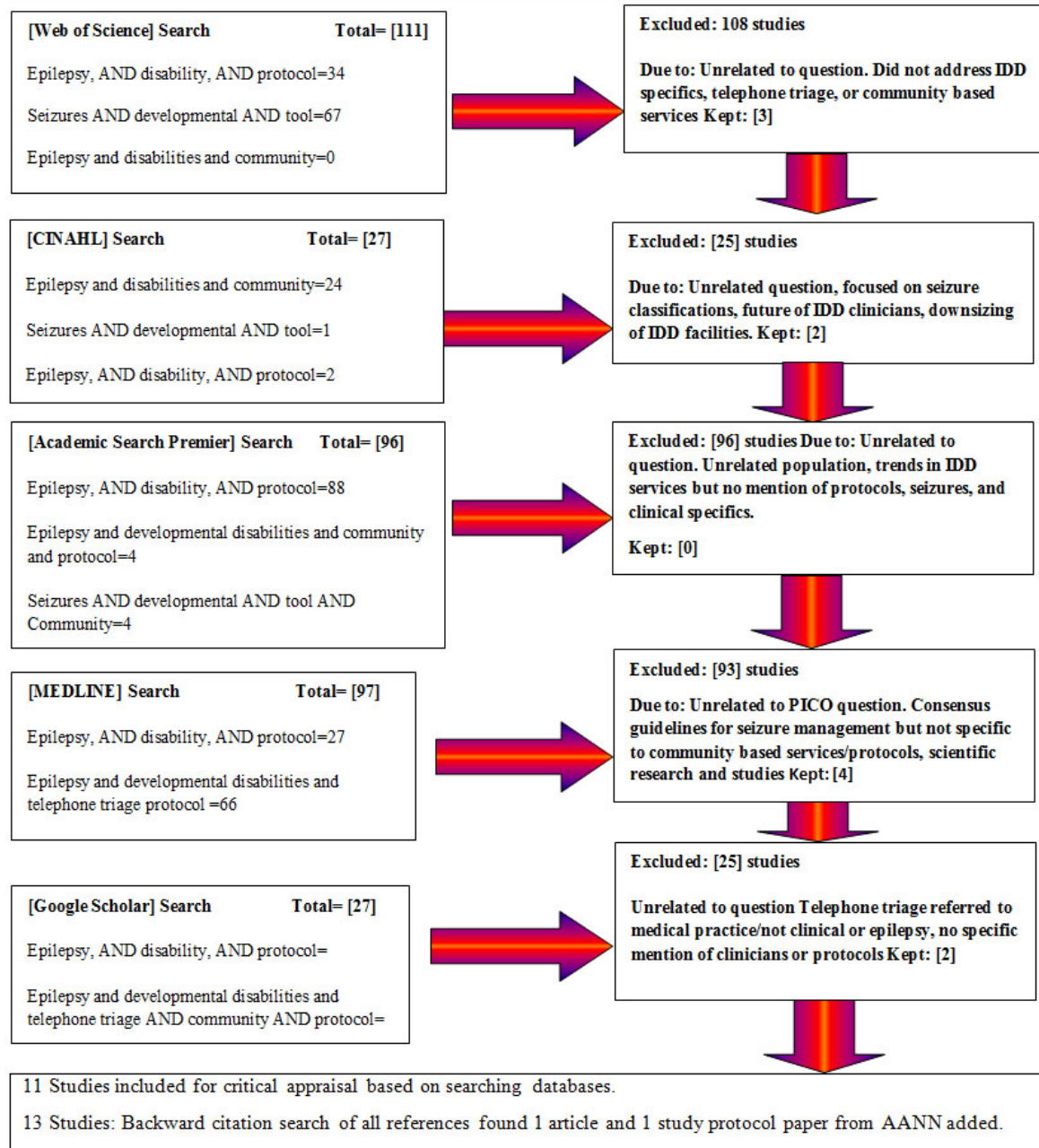


Figure 1. The literature search tracking and flow

4.2 Inclusion and exclusion criteria

This review considered all quantitative or descriptive studies that included a tool or protocol management for epilepsy with ID/DD persons in the community setting. Studies with outcomes/findings that included evidence-based decision mak-

ing protocol or tool which guided clinical management or next steps were subject to critical appraisal. Studies were excluded if the aims were not related to the question under study or not inclusive of the ID/DD population.

4.3 Assessment of methodological quality and data extraction

Standardized critical appraisal instruments from The Cochrane Collaboration^[36] were used to determine the appropriateness of each study for inclusion in the meta-synthesized findings. Assessment by a primary reviewer and second reviewer was carried out for methodological validity and to limit bias. Once each study was appraised and determined to be applicable for inclusion, data related to findings were extracted from papers and included in the review. Extracted data included specific details about the participants, the effects of the intervention tool or protocol, and outcomes of significance to the research question. Data pooling involved the aggregation or synthesis of findings. Results were reviewed for credibility of themes and findings supported by data. Lastly, data were subjected to a meta-synthesis analysis in order to produce a single comprehensive set of synthesized findings.

5. RESULTS

The electronic and hand search yielded a total of 358 research studies for screening. Exclusion criteria resulted in 11 articles for evaluation. Hand searching of all references for the final 11 articles resulted in the addition of one paper and one guideline. The study question specificity eliminated several papers from data extraction. Ultimately, only 6 of the 13 research papers appraised included a tool or protocol appropriate to the study question. Research articles included in the final synthesis are listed and described in Table 1. Due to the heterogeneous nature of the tools and outcomes, the studies are presented in a narrative summary, and a final meta-aggregated framework is presented.

Study participants included individuals with ID/DD, physicians, ID/DD and home health nurses, telephone triage nurses, and patients using call centers. The location of research studies encompassed a global perspective including research from: the United States, United Kingdom, Sweden, and Canada. A variety of settings were represented: community-based homes for persons with ID/DD, long-term care facilities, home healthcare settings, and telephone triage call centers. Interventions were comprised of educational methods, action research projects, risk awareness tools, competence-based assessments, and varied protocols related to telephone triage.

Due to a lack of quantitative research, several studies expressed the need for more robust research on the management of epilepsy in the ID/DD population. Multiple designs were apparent in the research studies but quantitative research was minimal. Studies related to the practice of telephone triage presented evidence suggesting the usefulness of protocols in

guiding care.

Furthermore, several themes emerged from the search. A general lack of clinician knowledge was identified as a barrier to quality care for the ID/DD population. Also apparent was the absence of evidence-based practice by clinicians to guide care. The deficiency of clinician preparedness together with varied DSP educational background, may produce healthcare disparities for this population. Notably, quality seizure management may be less in the ID/DD population than in the general public.

Overall, the summary of findings suggest that epilepsy management requires competent clinicians. These clinicians must rely on the use of both evidence-based practice tools and clinical expertise to appropriately guide care. These findings hold true for advice given through telephone triage. Specifically, persons with ID/DD and epilepsy require highly skilled clinicians. To support these clinicians, resources and evidence-based tools are needed.

6. DISCUSSION

The use of telephone protocols and evidence-based tools were supported by research studies.^[13,16,18] However, to date a reliable tool to manage epilepsy during telephone triage to guide ID/DD clinicians does not exist. Therefore, there is a significant need for such a tool.

An abundance of literature addresses the management of epilepsy.^[27-29] While the findings of the search revealed varied seizure management tools it is important to reiterate what these tools lacked. Tools for epilepsy management specific to telephone triage for community-based settings was not found. No tools explicitly for epilepsy management for the ID/DD population were discovered. It is also relevant to note that most tools contained medical terminology. This language may impede a tool's usefulness in the field of ID/DD when non-healthcare providers such as DSPs, are placing the telephone triage calls.

In order to appropriately guide ID/DD clinicians, a tool is needed. The absence of process and procedure in telephone seizure management creates a significant gap in care for individuals in community-based settings. This is especially significant if the seizure pattern changes. For example, the post-seizure stage is longer, an injury occurs, the rescue seizure medication is not effective, or the characteristics of the seizure changes. This breach in care management may lead individuals to seek emergency department (ED) care. While ED care can be life-saving, it can also be unnecessary and financially costly.^[37] An appropriate seizure telephone triage tool for clinicians may help reduce unnecessary ED visits.^[38,39]

Table 1. Overview of included studies

Authors	Methods	Setting	Participants	Purpose/Findings
American Association of Neuroscience Nurses (2009)	Literature Review from 1997-2007, PubMed/Medline and CINAHL.	Varied	Studies Included: Randomized Control without significant limitations or meta-analysis, Randomized Control with important limitations, Qualitative studies, case studies, Evidence from reports of expert committees	Purpose: There is little evidence-based nursing research on the topic of epilepsy. Findings: More evidence based research is needed for patients in both inpatient and outpatient settings to guide clinical care.
Cole, Pointu, Wellsted and Angus-Leppan (2010)	Purposive sampling method using Quantitative and Qualitative Measures to devise and revise tool	Community based settings for persons diagnosed with ID/DD and epilepsy	Learning disabilities (ID/DD) clinicians working in community based settings in Europe	Purpose: Evaluate the effectiveness of the epilepsy awareness checklist to measure risk. Findings: The epilepsy risk awareness checklist provides a measure of risk. This study suggests it is a useful tool for the care of people with disability and epilepsy.
Kerr, Scheepers, Arvio, Beavis, Brandt, Brown, Humber, Iivanainen, Louise, Martin, Marson, Prasher, Sinh, Veendrick, and Wallace (2009)	Delphi method of consensus	Six countries participated; Australia, Finland, Germany, Netherlands, United Kingdom, and the United States	Professionals with an interest and experience in the management of epilepsy in people with Intellectual Disability (ID)	Purpose: Determine international consensus guidelines in the management of epilepsy in adults with ID. Findings: The management of epilepsy in people with ID/DD demands high professional standards across a range of clinical domains.
Marklund, Strom, Mansson, Borgquist, Baigi, and Fridlund (2007)	Evaluate design of a digital support model	Primary healthcare settings using computer generated telephone triage	Telephone clinicians registered basic information regarding the patient, and the patients were followed up 2 weeks later by a telephone nurse experienced in telephone triage but not employed at the workplace to determine patient compliance outcomes and appropriateness of level of care recommendations provided by the telephone nurse	Purpose: Evaluate a telephone nurse triage model in terms of appropriateness of referrals to the appropriate level of care, patient's compliance with given advice and costs. Findings: The telephone nurse triage model showed adequate guidance for the patients concerning level of care. Also releases resources for the benefit of both patients and the healthcare system.
Mayo, Chang, and Omery, (2002)	Descriptive, prospective, correlational design	Seven California settings that included both telephone advice centers and clinics that operated 24 hours per day	Telephone advice clinicians employed within the seven advice centers/clinics	Purpose: Examine the use of protocols and guidelines by telephone clinicians; describe the availability and types of protocols, explain the frequency and use, measure the relationship between the availability and use of the protocols and the quality of the clinical process, and to measure the relationship between nurse characteristics and quality of the clinical process. Findings: Clinical importance of this study is that advice nurses may not need to completely rely on protocols to guide practice, but pair practice with clinical expertise.
While, A., Clark, L. (2013)	Multi-method design consisting of: Review of the Literature, Interviews and Focus Groups, Development and Refinement of the Competency Tool, Field Test of the Competency Tool	District general hospital in London, UK; acute ward and emergency department	People with ID/DD, Carers (clinicians or teachers of people with ID/DD), Experts in the field of ID/DD-Adult, clinicians in clinical practice	Purpose: To develop and test a competency assessment tool for adult trained clinicians caring for people with intellectual disabilities in the hospital. Findings: Use of the competency tool increases clinician knowledge and skill. Also informs educational provision of the workforce.

The ideal tool for epilepsy management via telephone triage may well be a diagram that uses an evidence-based practice (EBP) methodology to guide the ID/DD clinician. EBP integrates individual clinical expertise with the best clinical research evidence.^[40] An EBP approach would help to ensure the clinician individualized each seizure based on clinical proficiency. The epilepsy management tool would provide the research based evidence to enhance the clinician's expertise.

The tool should be designed to reflect that clinicians would be relying on verbal feedback, most often, from non-healthcare professionals (DSPs) working in community-based settings.^[19] The tool should be free of medical terminology. Common language would expand the tool's ability to streamline and clarify both questions and responses. The tool should use questions that produce yes or no responses from DSPs. The DSPs would answer each question posed by the clinicians. The DSPs responses would guide the clinicians to the next step of the diagram. The tool should also include cues that prompt clinicians to consider additional support based on the situation and setting (community-based). Additional support may include seeking emergency department care. It could also prompt the use of a rescue medication such as rectal diazepam, to help control the seizure activity.^[29]

The study by the AANN^[26] included an evidence-based seizure diagram that guides clinicians. This seizure management tool may be useful in guiding ID/DD clinicians during telephone triage. In current practice ID/DD clinicians are informed promptly by DSPs about changes that occur in the health status of the individuals they support. This notification includes seizure events.^[21,22] The AANN seizure management tool may act as a catalyst to improve the communication system already used in community-based settings. This tool may also have the potential to be adapted to meet the unique seizure management needs of the ID/DD population.

6.1 Current research synthesis

The purpose for conducting this synthesis was to evaluate the evidence for epilepsy management tools. When disseminated, a synthesis of research related to epilepsy management telephone triage tools may improve clinical outcomes for individuals with ID/DD residing within community-based settings. The results of this research synthesis is proposed to complement the literature in the following five ways:

- (1) Highlight current available seizure management tools.
- (2) Expose current available seizure management tools to guide clinicians during telephone triage.
- (3) Determine if telephone triage tools exist for epilepsy management in community-based settings.

- (4) Discern if telephone triage tools exist for persons with ID/DD.
- (5) Evaluate if telephone triage tools exist for epilepsy management that could be adapted for use in the ID/DD population residing within community based settings.

Promoting the use of evidence-based practice, coupled with clinician expertise, has the potential to increase clinician confidence. Increased clinician confidence may improve clinical decision-making resulting in improved care.

6.2 Limitations

This review is limited by the availability of published research. It is also limited by the existence of quantitative trials and lack of ID/DD research related to seizure management tools. However, findings can illuminate the gaps that are present in clinical practice related to telephone triage tools for epilepsy management. The results can be used to explore seizure management tool solutions.

6.3 Implications for future research

Based on review findings, directions for future research may fall within four general categories:

- (1) Increase quantitative studies on epilepsy and protocol use in the ID/DD population living in community-based settings.
- (2) Consider focused research studies to determine if revising current seizure management tools (such as the AANN tool) is a feasible option to meet the needs of the ID/DD population living in community-based settings.
- (3) Exploration to determine barriers to including intellectual and developmental disability healthcare in pre-licensure clinician curriculums.
- (4) Examine the role of the DSP and qualifications for designation as a DSP to determine the possible need for national standards.

7. SUMMARY

Epilepsy has a pervasive impact on the lives of people with intellectual and developmental disability.^[40] It also has critical implications for caregivers such as DSPs.^[19] The difficulty in providing appropriate care is further impacted by the complexity and diversity of epilepsy in this population.^[41] Limited clinician education and experience is concerning. Varied health training required for DSPs further complicates clinical decision-making when guiding care via telephone triage. The absence of telephone triage tools for seizure management and tools specific to individuals with ID/DD, necessitates a need for further research and development of

such tools. Based on the results of this review, two evidence-driven clinical practices are provided. The effectiveness of telephone triage and the need for guidelines, checklists, and competency tools to guide clinicians.

Importantly, telephone triage models were aligned with medical appropriateness of care and patients followed clinical advice.^[42] Studies verified that clinicians support the use of decision-making tools and would use them when they are provided.^[43] In addition, Ramsay et al.^[38] suggested that effective management of epilepsy requires a distinctive understanding of the needs of special populations (i.e., ID/DD). Approved plans can reduce the need for rescue medication or emergency services.

Additionally, persons with intellectual and developmental disability self-reported that healthcare providers lacked knowledge and experience regarding their health needs.^[44] Persons with ID/DD may experience limited access to service. Lack of DSP and healthcare provider knowledge, highlights the need for tools, checklists, and competency measures. Research results supported the use of tools to augment clinical decision-making.^[45,46] While and Clark^[47] pointed out that using a competency assessment tool to measure clinicians' knowledge regarding ID/DD persons may improve healthcare outcomes. Rajpura & Sethi^[48] emphasized the need

for training requirements for clinicians related to epilepsy. Telephone triage is common practice in the ID/DD field dictating the need for evidence-based tools to guide clinical decision-making.

Dissemination of a telephone seizure management tool alone will not ensure its use in refining epilepsy management for the ID/DD population. Such adoption and implementation requires clinicians, patients, families, and service providers to understand the importance of using these tools.^[49] Furthermore, it may be necessary to revise current healthcare curriculums for clinicians that include the healthcare intricacies of this population.^[8] The adoption of national standards for DSP education on the health needs of persons with ID/DD may enhance the effectiveness of their role on the healthcare team.^[19] The partnership between clinicians and DSPs is a critical relationship to ensure quality seizure management. Moreover, the pairing of specialized clinical education and the availability of evidence-based telephone triage epilepsy tools, may enhance clinical judgment. This improvement may allow for more individualized, patient-focused seizure care for this population.

CONFLICTS OF INTEREST DISCLOSURE

The author declares that there is no conflict of interest.

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